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ABSTRACT

The annotated bibliography is intended to assist professionals working to develop decision making skills in disabled youth. The 40 bibliographic citations date from 1981 to 1989 and are grouped into the following categories: health issues, psychosocial issues, and education and career issues. Fourteen training materials with information given concerning title, supplier, address, phone, date are described. Brief abstracts are also provided. (DB)

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National Center for Youth with Disabilities

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National
Center for

Youth with Disabilities

January 15, 1990

Dear Colleague:

The National Center for Youth with Disabilities (NCYD) is committed to raising awareness of the needs of adolescents with disabilities. In keeping with this mission, we have prepared a bibliography for professionals concerned about youth with disabilities and decision-making skills. We hope you will take the time to read through this bibliography and share it with anyone you believe would benefit from the information.

We also ask that you complete the enclosed evaluation form and return it in the postage paid envelope by February 9, 1990. The evaluation should take less than five minutes, and you are free to remain anonymous. Your evaluation is of great importance to us in that the responses will be used to help us improve our services. To those individuals who complete and return the evaluation, we are offering a **free** search (up to 25 references) of our database on a topic of your choosing.

Thank you for your consideration. If you have any questions or would like to request your free search of our database, please call us at 1-800-333-6293. Your help is greatly appreciated.

Sincerely,

Gayle Geber

Gayle Geber
Program Director
National Center for Youth
with Disabilities

Enclosures

A. *BIBLIOGRAPHIC MATERIALS*

I. HEALTH ISSUES

Decision-making issues in health care often involve significant ethical considerations as choices regarding treatment and can lead to life-threatening consequences. In the following references, ethics, compliance, competence to consent to treatment, and the role of families and professionals in health decision-making are discussed in light of the special developmental concerns for adolescents.

AUTHOR Smith PS; Goldman DS;
TITLE **Care of the young hemophiliac. New socioeconomic demands and the changing patient-physician relationship.**
SOURCE *Am J Pediatr Hematol Oncol* 1985 Summer; 7(2): 165-74;
ABSTRACT Discussion of legal and ethical issues including access to care, allocation of resources, avoidance of harm, informed consent, confidentiality and paternalism, using six case examples.

AUTHOR Bush EG; Magyar PH;
TITLE **Conflicting claims: An ethical dilemma in family-centered care.**
SOURCE *J Assoc Pediatr Oncol Nurses* 1986; 3(3): 9-12, 27;
ABSTRACT Through the example of a single case study, this article describes ethical nursing approaches to interpersonal conflict in cancer care decision making. Adolescent development is taken into account. The dilemma described is disagreement on treatment continuation between an adolescent patient and her family and physician. Approaches discussed include: utilitarian or goal-based, deontological or duty-based, and rights-based or advocacy approach.

AUTHOR Nitschke R; Humphrey GB; Sexauer CL; et al.;
TITLE **Therapeutic choices made by patients with end-stage cancer.**
SOURCE *J Pediatr* 1982 Sep; 101(3): 471-6;
ABSTRACT In this study, children and youth with end-stage cancer were openly informed of the recent progression of their disease, the unavailability of any other effective drugs, the improbability of a cure, and the imminence of death. Children were then given the opportunity to decide between two choices: continue chemotherapy with experimental drugs, or stop treatment and receive supportive care at home. Results indicate that those children who chose supportive care at home rarely suffered from depression or behavioral disturbances and benefited psychologically from improved communications with family and friends.

AUTHOR Deatrick JA;
TITLE **It's their decision now: Perspectives of chronically disabled adolescents concerning surgery.**
SOURCE *Issues Compr Pediatr Nurs* 1984; 7(1): 17-31;
ABSTRACT From an analysis of data gathered through structured interviews and observations of adolescents and their parents, a structural framework was derived from the critical events and management strategies that emerged. In particular, the decision to have surgery was examined: the content/meaning of the decision; strategies used to manage the decision; evaluation of the event and its management; and clinical, theoretical, and research implications of findings.

AUTHOR Blum RW;
TITLE **Compliance in the adolescent with chronic illness.**
SOURCE *Semin Adol Med* 1987 Jun; 3(2): 157-62;
ABSTRACT This article discusses issues surrounding compliance with medication, lifestyle changes, medical procedures, and appointments. Direct and indirect measures are discussed, including benefits and drawbacks. Factors found to correlate positively with compliance are: family supportiveness, positive family communications, positive family expectations of therapeutic outcome, family involvement, reasonable cost in both time and money, convenience, private providers, consistency of providers, perceived severity of illness, perceived efficacy of treatments, and level of symptom relief. Prospective measures of compliance are suggested, and a list of clinical approaches for improving compliance is provided. The author compares common perceptions of adolescent compliance with empirical findings and adolescent development.

AUTHOR Plotkin R;
TITLE **When rights collide: Parents, children, and consent to treatment.**
SOURCE *J Pediatr Psychol* 1981 Jun; 6(2): 121-130;
ABSTRACT Review of legal literature; discussion of situations where parental consent is not required, focusing on adolescents.

AUTHOR Gaylin W;
TITLE **The "competence" of children. No longer all or none.**
SOURCE *J Am Acad Child Psychiatry* 1982 Mar; 21(1): 153-62;
ABSTRACT Attempts to define conditions that limit competence; implications for minors' right to consent, for involvement of adolescents in decisions affecting their health.

AUTHOR Adelman HS; Kaser-Boyd N; Taylor L;
TITLE **Children's participation in consent for psychotherapy and their subsequent response to treatment.**
SOURCE *J Clin Child Psychol* 1984 Summer; 13(2): 170-8;
ABSTRACT Results of this study indicated that few youth actually participate in their own referral to psychotherapy and that this does not always reflect a lack of competence among the youth to do so. With regard to psychotherapy itself, 75% of these adolescents consented to treatment, only 60% indicated strong interest in beginning, and only 31% were deemed "motivationally ready" by the psychologists. Thus, although agreeing to treatment increased the likelihood of motivational readiness, and motivational readiness was associated with positive treatment adjustment and outcome, perceived choice is not the only important factor effecting level of commitment.

AUTHOR Kaplan EH;
TITLE **The dilemma of disposition: Psychiatric decision-making and the college-bound high school senior.**
SOURCE *Adolesc Psychiatry* 1982; 10: 469-83;
ABSTRACT The transition from high school to college can be stressful and sometimes motivates adolescents to seek psychiatric treatment. Decisions regarding the type and timing of treatment are made more difficult because of the impending separation of the student from the family. Several case studies illustrate different ways of treating college-bound adolescents with emotional disorders.

AUTHOR Cohen DG;
TITLE **Treatment refusal in adolescents.**
SOURCE *Semin Oncol Nurs* 1986 May; 2(2): 112-6;
ABSTRACT Discusses non-compliance on a continuum from complete refusal of treatment to unwillingness to cooperate with a specific aspect. This issue is particularly important when teens reach the age of consent. Two case studies are used to illustrate the factors associated with non-compliance: intrapsychic issues, peer relationships, family issues, and religion. The clinical implications of treatment refusal and possible interventions are described.

AUTHOR Orr ML;
TITLE **When only perfect health will do.**
BOOK *Positive Approaches to Living With End Stage Renal Disease. Psychosocial and Thanatological Aspects.*
EDITOR Hardy MA; Appel GB; Kiernan JM;
SOURCE Praeger: New York, 1986: 152-7;
ABSTRACT Through this case study of a young adult, female kidney transplant patient, the author discusses the role which individual standards play in determining quality of life. For this patient, renal disease and transplant precipitated psychological problems due to her dissatisfaction with a life she perceived as imperfect. Professional and family concerns are described. Eventually, this patient effected her own death through noncompliance with treatment.

AUTHOR Gilgoff I; Prentice W; Baydur A;
TITLE **Patient and family participation in the management of respiratory failure in Duchenne's muscular dystrophy.**
SOURCE *Chest* 1989 Mar; 95(3): 519-24;
ABSTRACT This article reports on the experiences of a clinic established specifically for patients facing impending respiratory failure resulting from Duchenne's muscular dystrophy. Previous studies had indicated that such respiratory failure was predictable and that patients and their families felt a need for more education and psychosocial support services when facing death from disease. This clinic attempted to provide more education and support and the opportunity for patients to make decisions regarding mechanical ventilation prior to actual respiratory failure. Descriptive data are discussed; case examples are included. The authors suggest that the methods used at this clinic are valuable tools for facilitating active participation of family and patient as part of the health care team.

AUTHOR Maynard FM; Muth AS;
TITLE **The choice to end life as a ventilator dependent quadriplegic.**
SOURCE *Arch Phys Med Rehab* 1987 Dec; 68(12): 862-4;
ABSTRACT Case study of a 19-year-old male who chose to be disconnected from his ventilator 25 months after the diving accident which caused his total motor and sensory quadriplegia. Physical, medical, psychosocial, and legal circumstances are detailed. Rehabilitation staff were said to be particularly disturbed by the patient's decision due to his wealth of resources not often available to individuals who have quadriplegia and are ventilator-dependent (e.g., social support, assistive equipment, accessible home services, personal assets). The authors suggest that working toward a legal end to his life, one that would not cause his family undue hardship, may have given meaning to this patient's post-injury experience.

AUTHOR Bunch WH; Chapman RG;
TITLE **Patient preferences in surgery for scoliosis.**
SOURCE *J Bone Joint Surg* 1985 Jun; 67(5): 794-9;
ABSTRACT This study surveyed teen-age patients, their parents, their surgeons, and other health professionals as to their scoliosis surgery preferences. Conjoint analysis, a technique borrowed from the fields of marketing and psychology, was employed to specifically discover respondents' preferences within the context of necessary trade-offs between options. In all groups, the risk of nerve damage emerged as the most important consideration, followed by the risk of reoperation, curve correction, and aftercare. It appears, from this study, that the values of patients, their families, and health care providers are in agreement on this issue.

AUTHOR Levenson PM; Pfefferbaum BJ; Copeland DR; et al.;
TITLE **Information preferences of cancer patients ages 11-20 years.**
SOURCE *J Adol Health Care* 1982 Aug; 3(1): 9-13;
ABSTRACT Preferred sources of information analyzed by diagnosis, race, gender, time since diagnosis, and phase of illness. Overall, physicians were the most frequently preferred source of information.

II. PSYCHOSOCIAL ISSUES

Psychosocial issues either affecting or resulting from specific decision-making processes entail a wide range of concerns: sexuality, risk-taking, privacy, family relations, moral judgments, and self-esteem. Discussed with reference to professionals, adolescents, and their families, the following references elaborate on these concerns.

AUTHOR Jaffe LR; Aledort L;
TITLE **Adolescents with hemophilia: Psychosocial and sexual implications of infection with the Human Immunodeficiency Virus.**
SOURCE *J Adol Health Care* 1988 May; 9(3): 261;
ABSTRACT An abstract of a paper presented at the 1988 Annual Meeting of the Society for Adolescent Medicine. Fifteen adolescents who had received multiple infusions of clotting factor were interviewed. Twelve patients were aware of the association between AIDS and hemophilia; 3 denied knowing this. Five knew they were HIV positive, 2 did not want to know, 1 asked to know his HIV status, and 7 did not know. Before becoming aware of AIDS, 5 were selective in telling others of their hemophilia; since AIDS, 4 more patients have kept their disease discreet. The adolescents were more worried about rejection from sexual partners than developing AIDS. Other findings are also reported.

AUTHOR Senft KR; Eyster ME; Haverstick J; et al.;
TITLE **Risk-taking and the adolescent hemophiliac.**
SOURCE *J Adol Health Care* 1981 Dec; 2(2): 87-91;
ABSTRACT It is a commonly held belief that adolescents with hemophilia tend to exhibit more interest in physical risk-taking behavior than do adolescents without hemophilia. In this study, a self-administered questionnaire was used to determine risk-taking attitudes, anticipated risk-taking behaviors, and the apparent likelihood of carrying out those behaviors. Results indicate that adolescents with hemophilia do not exhibit greater risk-taking attitudes, anticipate greater risk-taking behavior, or appear more likely to carry out those behaviors than adolescents without hemophilia.

AUTHOR Ditunno PL; McCauley C; Marquette C;
TITLE **Sensation-seeking behavior and the incidence of spinal cord injury.**
SOURCE *Arch Phys Med Rehab* 1985 Mar; 66(3): 152-5;
ABSTRACT This study used Zuckerman's Sensation-Seeking Scale (SSS) and lay-raters to determine the degree of sensation-seeking behavior among study participants. The SSS measures four components: thrill and adventure-seeking; experience-seeking; disinhibition; and boredom susceptibility. Analysis was stratified by age group. Findings indicated no significant differences between individuals with and without spinal cord injuries. The authors contend that this is strong evidence that there is not a premorbid personality trait that distinguishes those who later sustain spinal cord injury.

AUTHOR Linden PG; Hostler SL; Nathan M;
TITLE **Sexuality and the physically handicapped adolescent.**
SOURCE *J Adol Health Care* 1981 Sep; 2(1): 81;
ABSTRACT An abstract of a paper presented at the Annual Meeting of the Society for Adolescent Medicine, Oct. 1981. This research illustrates the need for health care services that include continuous education about one's disability, body functions, vocational possibilities and sexuality. For this population to reach maturity, they need knowledge to gain control over their lives, become less dependent on their families, and make realistic choices.

AUTHOR Guyer MJ; Harrison SI; Rieveschl JL;
TITLE **Developmental rights to privacy and independent decision-making.**
SOURCE *J Am Acad Child Psychiatry* 1982 May; 21(3): 298-302;
ABSTRACT Review of historical aspects of parental decision making; current issues in child rights; argument for use of developmental rather than chronological criteria.

AUTHOR Brotherson MJ; Houghton J; Turnbull AP; et al.;
TITLE **Transition into adulthood: Parental planning for sons and daughters with disabilities.**
SOURCE *Educ Train Mentally Retard* 1988 Sep; 23(3): 165-74;
ABSTRACT Transition into adulthood for young adults with disabilities is a major concern for families, advocates and professionals. Through telephone interviews with 48 parents of young adults with mental and physical disabilities, this study examined some aspects of parent planning for adult needs and the relationship of that planning to family functioning. The greatest needs identified by parents were residential, socialization, and employment. There was a positive relationship between planning for adult needs and family functioning, and a positive relationship between using social supports in planning and family functioning.

AUTHOR Turnbull HR; Turnbull AP; Bronicki GJ; et al.;
BOOK **Disability and the Family: A Guide to Decisions for Adulthood.**
SOURCE Paul H. Brookes: Baltimore, 1989; 432;
ABSTRACT Practical information and steps for planning for the future of adolescents with disabilities. Includes legal, social-interpersonal, vocational, and residential options. Methods for self-assessment, self-advocacy, and lists of resources to assist in planning are included.

AUTHOR MJS;
TITLE **"Let Me Make My Own Decisions" — An adolescent reaches for independence.**
SOURCE *Except Parent* 1987 Mar; 17(2): 9-12;
ABSTRACT This case study presents issues of independence and over-protectiveness relevant to a 16-year-old female with a disability and her family. The author presents a conflict from perspectives of various family members. Cooperative discussion is facilitated. A creative resolution evolves and the family learns new coping strategies as a result.

AUTHOR National Information Center for Children andYouth with Handicaps;
TITLE **Transition summary: Self-determination.**
SOURCE NICHCY, P.O. Box 1492, Washington, D.C. 20013, 1-800-999-5599;
ABSTRACT Five articles on self-determination, transitioning to adulthood, the role of the family, anger in young adults with disabilities, and a role model with a disability. Guidelines for parents in helping children achieve self-determination are provided, as well as a bibliography and list of organizations dealing with transition issues.

AUTHOR Derr AM;
TITLE **How learing disabled adolescent boys make moral judgements.**
SOURCE *J Learning Disabil* 1986 Mar; 19(3): 160-4;
ABSTRACT In this study, adolescents with learning disabilities were found to exhibit significantly less mature moral development than their nondisabled peers. The Moral Judgment Interview was used to determine study participants' moral development in terms of Kohlberg's six stage framework. Youth with learning disabilities used moral reasoning that was more egocentric than their peers. They lacked a comprehensive social perspective, had a harder time delineating options for action, and were less able to anticipate the consequences of each option and from different perspectives. Findings suggest that moral, social, and psychological development are interdependent. Theoretical foundations for the deficits among youth with learning disabilities and specific interventions to facilitate moral development are provided.

AUTHOR Fine E;
TITLE **Are we preparing adolescents with learning disabilities to cope with social issues?**
SOURCE *J Learning Disabil* 1987 Dec; 20(10): 633-4;
ABSTRACT The purpose of this study was to determine whether or not adolescents with learning disabilities were being presented with information about social issues in comparison to their nondisabled peers. Social skills deficits, poor thinking skills, and a weak information base are suggested correlates affecting decision-making ability and predispose these adolescents to social vulnerability. The results indicated that both groups of students were presented with little information about current social issues, but students with learning disabilities received less than students without learning disabilities.

AUTHOR Smith SL;
TITLE **Preparing the learning disabled adolescent for adulthood.**
SOURCE *Child Today* 1988 Mar; 17(2): 4-9;
ABSTRACT General review of skills necessary for adulthood that affect adolescents with learning disabilities: planning and organizational skills, responsibilities, language skills, socialization skills, problem solving and critical thinking skills, self-esteem, stress, and self-advocacy.

AUTHOR Schultz JB; Adams DU;
TITLE **Family life education needs of mentally disabled adolescents.**
SOURCE *Adolescence* 1987 Spring; 22(85): 221-30;
ABSTRACT The Family Life Information Inventory, modified to accommodate reading and comprehension levels of adolescents with mild or minimal mental retardation, was administered to the participants of this study. Data indicated unmet needs in six areas: basic nutrition, teenage pregnancy, developmental tasks of adolescence, sex education, marriage and parenthood, and planning/decision making. Participants indicated that they wanted more help with: decisions regarding pregnancy, setting goals and making plans, responsibilities for and effects of decisions on self and others. The authors conclude that findings indicate a strong desire to become independent, responsible decision makers among these adolescents. They suggest that family life education curricula should emphasize skills and knowledge in these areas of unmet need.

III. EDUCATION AND CAREER ISSUES

Decision-making with respect to educational and vocational issues involves adolescents' ability and willingness to participate in the planning processes; decision-making is also considered to be the goal or outcome of the planning process. The following references explore these issues regarding high school, college, and vocational placement.

AUTHOR Adelman HS; Lusk R; Alvarez V; et al.;
TITLE **Competence of minors to understand, evaluate, and communicate about their psychoeducational problems.**
SOURCE *Prof Psychol Res Practice* 1985 Jun; 16(3): 426-34;
ABSTRACT Adolescents with learning and behavior problems have often been viewed as insufficiently competent to participate in decisions about their own psychoeducational treatment. These researchers examined the effect of explicit versus presumed consent or competence and self-estimates of competence. Math problems were the tasks the youths performed. In general, results indicated that these adolescents were able to understand instructions and tasks, make accurate self-estimates, convey explanations, and stay on task. Overestimates of competence, a finding in previous studies of youth with behavior and learning problems, were more common under conditions where explicit consent of the adolescent was not sought. The authors suggest that adolescent aversion to and poor performance in treatment decision making may be ameliorated by providing youth with more choices regarding participation.

AUTHOR Taylor L; Adelman HS; Kaser-Boyd N;
TITLE **Perspectives of children regarding their participation in psychoeducational decisions.**
SOURCE *Prof Psychol Res Practice* 1983 Dec; 14(6): 882-94;
ABSTRACT In this study, students in a program designed to address learning and behavior problems were asked to state their desires regarding participation in the planning of their own education and treatment. Most students wanted to participate in such decisions, perceived themselves as capable of such participation, and did not expect negative effects from participation. Most students' behavior was consistent with these stated intentions and expectations: they did participate in decisions, judged their actions effective, and few experienced negative effects.

AUTHOR Taylor L; Adelman HS; Kaser-Boyd N;
TITLE **Minors' attitudes and competence toward participation in psychoeducational decisions.**
SOURCE *Prof Psychol Res Practice* 1985 Apr; 16(2): 226-35;
ABSTRACT This replication of a 1983 study found similar results: that most youth want to be involved in psychoeducational decisions; that they perceive themselves as competent to do so; that they know what outcomes they want; and that they follow through if given the opportunity. Going beyond the first study: age was positively correlated with interest and follow-through; most participants wanted to improve their skills regarding the psychoeducational decision-making process; parents and teachers rated the effectiveness of the adolescents who participated as high. The authors suggest that these data indicate the value of offering instruction in effective participation along with participation itself.

AUTHOR Mithaug DE; Martin JE; Agran M;
TITLE **Adaptability instruction: The goal of transitional programming.**
SOURCE *Except Child* 1987 Apr; 53(6): 500-505;
ABSTRACT This article describes adaptability instruction for adolescents with mental retardation as an instructional model which is intended to teach students to adapt to changes in work environments. The model includes four components: a) decision making; b) independent performance; c) self-evaluation; and d) adjustment. It is suggested that further development is needed in the area of adaptability instruction in order to facilitate the employability of students with handicaps.

AUTHOR Schleifer MJ;
TITLE **"Junior high school is a zoo"—The youngster with emotional problems in school.**
SOURCE *Except Parent* 1981 Aug; 11(4): 45-52;
ABSTRACT Case presentation of the family decisions involved with the choice of school for an adolescent with emotional problems.

AUTHOR Agran M;Martin JE;Mithaug DE;
TITLE **Achieving transition through adaptability instruction.**
SOURCE *Teaching Exceptional Children* 1989 Winter; 21(2): 4-7;
ABSTRACT Students with learning and behavior problems often experience failure when they enter the world of work. Two major reasons are their need for a great deal of supervision and their inability to respond appropriately to the many changes that occur in work environments. This article provides teachers and work specialists with an instructional model to teach adaptability skills and presents recommendations to promote problem solving skills.

AUTHOR McGuire JM; Shaw SF;
TITLE **A decision-making process for the college-bound student: Matching learner, institution, and support program.**
SOURCE *Learn Disab Q* 1987 Spr; 10(2): 106-11;
ABSTRACT This article describes a systematic approach to making choices about postsecondary education for adolescents with learning disabilities. The framework takes into account the perspectives of students, parents, and high school personnel. Three components are involved: characteristics of the student, characteristics of the institution, and characteristics of the learning disability support program. The McGuire-Shaw Postsecondary Selection Guide for Learning Disabled Students (MSG) is described, and excerpts from the instrument are provided. The MSG is designed for use by guidance counselors to facilitate student decision making in this area.

AUTHOR Vogel SA;
TITLE **Creating "safety nets" in residential settings.**
SO *J Postsecond Ed Disabil* 1988 Summer; 6(3): 3-6;
ABSTRACT Prompted by the tragic death of a postsecondary student with diabetes, a number of preventive guidelines are suggested for school and residential staff: seriously medically ill students should agree to full disclosure, a communication network should be devised, and a case manager should be designated to assure compliance with medical care.

AUTHOR Biller EF;
TITLE **Career development of the learning disabled adolescent. A focus on career maturity.**
SOURCE *Career Dev Excep Indiv* 1985 Spring; 8(1): 17-22;
ABSTRACT This article discusses career maturity, or the readiness to make the educational and career decisions expected of them, among adolescents. Adolescents with learning disabilities have been found to be less career-mature than their non-disabled peers, perhaps due to the psychological effects of labelling or to the dearth of career development opportunities for students with learning disabilities who are not college bound. Suggestions are made regarding approaches to assessing and fostering the development of career maturity. Empirical data indicate that career maturity in high school is predictive of later career satisfaction and adjustment.

AUTHOR Czerlinsky T; Jenson R; Pell KL;
TITLE **Construct Validity of the Vocational Decision-Making Interview (VDMI).**
SOURCE *Rehab Counsel Bull* 1987 Sep; 31(1): 28-33;
ABSTRACT Researchers investigated the validity of a Vocational Decision-Making Interview (VDMI) on rehabilitation clients with physical, mental, or emotional disabilities. Results indicate the VDMI is valid, and is a useful tool for identifying vocational decision-making problems, service needs of the individual with disabilities, and the development of new vocational education programs.

AUTHOR Kiernan WE; Stark JA;
TITLE **Employment options for adults with developmental disabilities: A conceptual model.**
SOURCE *Remed Spec Ed* 1986 Nov; 7(6): 7-11;
ABSTRACT The model "Pathways to Employment" is discussed. The model stresses individuality and availability of simultaneous choices. Supported employment is discussed in relation to individual needs.

AUTHOR Wehman P; Moon MS; Everson JM; et al.;
BOOK **Transition from School to Work—New Challenges for Youth with Severe Disabilities.**
SOURCE Paul H. Brookes Publishing Co.: Baltimore, MD, 1988; 332;
ABSTRACT Provides guidance to make transition planning and implementation more effective. Outlined are three basic steps leading to successful vocational placement: early planning in school years, developing and implementing a comprehensive Individual Transition Plan (ITP), and determining and choosing employment possibilities. Book provides sample forms, charts, tables, and lists which can be adapted.

B. TRAINING MATERIALS

The training materials listed below are appropriate for use either in direct service or professional development regarding decision-making for youth with a wide range of chronic illnesses or disabilities covering diverse issues: prevention, community services, and social support.

TITLE	**You Can Do It! A Guide to Maryland Services for Young Adults with Developmental Disabilities**
SUPPLIER	Katherine Hax
ADDRESS	Developmental Disabilities Council, One Market Center, Box 10, 300 West Lexington Street, Baltimore, MD 21201
PHONE	(301) 333-3688
DATE	1986
ABSTRACT	This free booklet addresses questions about work, residence, transportation, service delivery, and living in the community. It is printed with large type and uses easy-to-read language. It is designed to provide young people with developmental disabilities with suggested resources and solutions for day-to-day problems.

TITLE	**Don't Just Sit in a Big Green Chair! - Living with Juvenile Rheumatoid Arthritis**
SUPPLIER	LaRabida Children's Hospial, Rheumatology Program
ADDRESS	E. 65th Street at Lake Michigan, Chicago, IL 60649
PHONE	(312) 363-6700
DATE	1985
ABSTRACT	This 16 page booklet is geared towards the adolescent and how he/she can cope with juvenile rheumatoid arthritis. It includes a brief description of the disease and how to live with it. Areas such as school, sports, social activities and sexuality are addressed in a manner that can easily be understood. (Available for $1.50 from LaRabida at Extension #520.)

TITLE	**Space Age Smarts**
SUPPLIER	Florida Association of Pediatric Tumor Programs
ADDRESS	P.O. Box 13372, University Station, Gainesville, FL 32604
PHONE	(904) 375-6848
DATE	1987
ABSTRACT	Space Age Smarts is an 8 1/2"x11", 12-page, full color comic book designed for hemophiliacs aged 13-16 years. An alien from the Center of Galactic Health learns about AIDS from a group of teenage earthlings. This cleverly written and imaginatively illustrated comic book encourages common sense precautions to prevent the spread of AIDS. The teens, including one with hemophilia, discuss: transmission, safer sex practices, the dangers of shooting-up, and the importance of people with hemophilia cleaning up their blood spills and disposing of needles. The fact sheet inside the back cover presents more detailed information on what AIDS is, how it is transmitted, the AIDS antibody test, symptoms, and prevention. (Purchase price is $1.95)

TITLE	**Wasted Dreams**
SUPPLIER	Southeastern Michigan Spinal Cord Injury System
ADDRESS	Rehabilitation Institute, 261 Mack, Detroit, MI 48201
PHONE	(313) 745-9876
DATE	1988
ABSTRACT	Wasted Dreams discusses choices made by adolescents that may predispose them to spinal cord injuries. Specific issues are interpersonal violence and gun shootings. The notion that choices are made by individuals either to take risks or avoid risks is stressed. Consequences are discussed by youth with disabilities. (Purchase price is $20.00 for 1/2" and $50.00 for 3/4". Free loan in Detroit area.)

TITLE	**Hey! New Wheels**
SUPPLIER	Southeastern Michigan Spinal Cord Injury System
ADDRESS	Rehabilitation Institute, 261 Mack, Detroit, MI 48201
PHONE	(313) 745-9876
DATE	1986
ABSTRACT	Hey! New Wheels discusses choices made by adolescents in a variety of settings that may predispose them to spinal cord injuries. This video will rivet in students minds the devastating and irreversible consequences of a spinal cord injury. (Purchase price is $20.00 for 1/2" and $50.00 for 3/4". Free loan in Detroit area.)

TITLE	**Making Love-Etc. A Booklet for Young People with Physical Disabilities**
SUPPLIER	Nursing Office
ADDRESS	Bloorview Childrens Hospital, 25 Buchan Court, Willowdale, ON M2J4S9
PHONE	(416) 494-2222
DATE	1985
ABSTRACT	People with physical disabilities can and do give and receive sexual pleasure in a variety of ways. All it takes is knowledge, self-acceptance, consideration for others, imagination and patience. This booklet explores some myths and explains some problems. It then goes futher and offers some solutions. (Purchase price is $6.00 prepaid Canadian funds.)

TITLE	**Learning Experiences for Physically Disabled and Chronically Ill Adolescents**
SUPPLIER	Kluge Children's Rehabilitation Center
ADDRESS	2270 Ivy Road, Charlottesville, VA 22901
PHONE	(804) 924-5161
DATE	1986
ABSTRACT	A manual which suggests activities to use with early adolescents to improve social skills, independence, comfort in the community and assertiveness with health care professionals. Also includes exercises addressing health education issues, e.g., eating, smoking, drinking. (Purchase price: $4.00)

TITLE **Issues of Independence**
SUPPLIER Young Adult Institute, PID Tapes
ADDRESS 460 West 34th Street, New York, NY 10001
PHONE (212) 563-7474
DATE 1986
ABSTRACT Letting go and allowing a developmentally disabled adolescent his/her independence can be a dilemma for parents. Two parents talk about their personal experiences adjusting to their sons' emerging adulthood and advise other parents to take small steps and acknowledge their adolescent's right to make mistakes. This show also highlights three developmentally disabled individuals who share their successes and struggles for independence. (30 minute videotape available on 1/2" and 3/4". Rental: $45 plus $4 shipping; Purchase: $75 plus $4 shipping)

TITLE **Students in Transition Using Planning**
SUPPLIER PACER Center
ADDRESS 4826 Chicago Avenue, Minneapolis, MN 55417-1055
PHONE (612) 827-2966
DATE 1988
ABSTRACT Total package needed to present a series of three workshops to students with handicaps at the secondary level: 1) a) A Resource Manual with outlines for each session that organize and explain the concepts to be introduced, activities in which students participate, and information handouts that explain topics such as financial aid programs, accessing employment, housing options, and post-secondary education or vocational training programs; b) A set of 45 transparencies that accompany the classroom sessions for students. Total package cost = $280.00 (order #ST1); 2) Resource Manual sold separately = $10.00 @ (order #ST2); 3) Set of transparencies sold separately = $270.00/set (order #ST3). 4) Set of three information pieces for secondary students who are mentally retarded (topics: vocational rehabilitation, social work services, and self advocacy) Cost $1.00/set (order #ST4).

TITLE **Guardianship**
SUPPLIER Young Adult Institute, PID Tapes
ADDRESS 460 West 34th Street, New York, NY 10001
PHONE (212) 563-7474
DATE 1986
ABSTRACT This show focuses on protecting the rights of an adolescent with developmental disabilities, after age 21, through guardianship. Dr. Ruth Luckasson defines guardianship and a panel of experts, including an attorney and sibling, weigh the pros and cons and debate how much power a guardian actually has. The process, procedure and legal issues to keep in mind when making this decision are also reviewed. (30 minute videotape available on 1/2" and 3/4". Rental: $45 plus $4 shipping; Purchase: $75 plus $4 shipping)

TITLE **The Case Management Team: Building Community Connections**
SUPPLIER Metro Council Data Center
ADDRESS Mears Park Centre, 230 East 5th Street, St. Paul, MN 55101
PHONE (612) 291-8140
DATE 1988
ABSTRACT Multi-media resource to explain case management: changes in the service system, case management that addresses human values, the integration philosophy, a team approach to case management decisions, and building community capacity to support integration. (The set of materials includes a 15 minute videotape on 1/2", a 10 minute audiotape, and book. The entire set is available for purchase at $20.00. The book alone is $3.00.)

TITLE **A New Way of Thinking**
SUPPLIER Governor's Planning Council on Developmental Disabilities
ADDRESS MN State Planning Agency, 300 Centennial Office Bldg., 658 Cedar Street, St. Paul, MN 55155
PHONE (612) 296-9963
DATE 1988
ABSTRACT This is a national award-winning videotape about the importance of community integration for individuals with severe disabilities. The tape is divided into four segments focusing on early family support, education of individuals with developmental disabilities, transition from school to employment, and supported living arrangements. Each topic features an individual who has participated in local community-based programs and services and who is successfully integrated into the community. The tape is motivational and informative. Useful as means of promoting positive philosophy towards people with disabilities and effective service strategies. (Available on 1/2", 3/4", and Beta for free loan or $30.00 purchase and shipping price.)

TITLE **Help Yourself: Tips for Teenagers with Cancer**
SUPPLIER Office of Cancer Communications
ADDRESS National Cancer Institute
Building 31, Room 10A24
Bethesda, MD 20892
PHONE 1-800-4-CANCER
DATE 1983
ABSTRACT This 40 minute free audiotape includes four radio-play stories entitled "The Day They Told You", "Your Family", "Your Treatment", and "Your Friends". This tape is designed to provide information and support for adolescents with cancer. May be used in conjunction with accompanying booklet.

TITLE	**Approaching the Future: Cystic Fibrosis in Adulthood**
SUPPLIER	Cystic Fibrosis Care & Teaching Center
ADDRESS	1935 Motor Street, #316 Dallas, TX 75235
PHONE	(214) 920-2361
DATE	1986
ABSTRACT	This 43-minute audiotape of an adult group was the project of a committee comprised of two social workers and several adult CF patients. The adult group has the desire to convey a more positive perspective on day-to-day coping with CF. During this videotape, the group discusses such issues as developing a successful adult group and why these groups are so important. Other issues include independence, employment, dating, marriage, childbirth, and dealing with the losses of group members through death. The goal of this presentation is to provide caregivers, CF adults, and CF teenagers with some helpful insights into the world that revolves around having CF. (Available for $50.00 plus $2.00 postage.)

CYDLINE Reviews

Please copy and share the contents of this publication. We ask that you credit the National Center for Youth with Disabilities as the source of information.

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